Gastrointestinal Carcinoid Tumor Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Gastrointestinal Carcinoid Tumors Be Found Early?
- Signs and Symptoms of Gastrointestinal Carcinoid Tumors
- How Are Gastrointestinal Carcinoid Tumors Diagnosed?

Stages and Outlook (Prognosis)

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- How Are Gastrointestinal Carcinoid Tumors Staged?
- Survival Rates for Gastrointestinal Carcinoid Tumors

Questions to Ask About Gastrointestinal Carcinoid Tumors

Here are some questions you can ask your cancer care team to help you better understand your cancer diagnosis and treatment options.

- What Should You Ask Your Doctor About Gastrointestinal Carcinoid Tumors?

Can Gastrointestinal Carcinoid Tumors Be Found Early?
Because carcinoid tumors usually grow and spread slowly, about half of all gastrointestinal carcinoid tumors are found in an early or localized stage, usually before they cause any problems.

Carcinoid tumors often are found incidentally (by accident). These tumors aren’t causing any symptoms but are found when tests are done for other diseases. They may also be found when parts of the gastrointestinal system are removed to treat other diseases.

For example, a person with stomach pain or bleeding may have a test called an upper endoscopy to look for an ulcer. In this test, the doctor looks at the stomach lining through a flexible lighted tube. During this test, the doctor may notice a small bump in the stomach wall that turns out to be a carcinoid tumor.

Sometimes during colorectal cancer screening, a routine sigmoidoscopy or colonoscopy (looking at the large bowel through a flexible lighted tube) will incidentally find a small carcinoid tumor.

Sometimes when the appendix is removed (to treat appendicitis or as part of a larger operation), a small carcinoid is found at the tip. This happens in about 1 of every 300 people who have appendix surgery done for other diseases. Most of these carcinoids were too small to have caused any symptoms.

## Signs and Symptoms of Gastrointestinal Carcinoid Tumors

Most gastrointestinal (GI) carcinoids grow slowly. If they do cause symptoms, they tend to be vague. When trying to figure out what’s going on, doctors and patients are likely to explore other, more common possible causes first. This can delay a diagnosis, sometimes even for several years. But some do cause symptoms that lead to their
Symptoms by location of the tumor

The symptoms a person develops from a GI carcinoid tumor often depend on where it is.

The appendix

People with tumors in their appendix often don’t have symptoms. If it is discovered, it is usually when they have their appendix removed during an operation for some other problem. Sometimes, the tumor blocks the opening between the appendix and the rest of the intestine and causes appendicitis. This leads to symptoms like nausea, vomiting, and abdominal (belly) pain.

The small intestine or colon

If the tumor starts in the small intestine, it can cause the intestines to kink and be blocked for a while. This can cause cramps, belly pain, weight loss, fatigue, bloating, diarrhea, or nausea and vomiting, which might come and go. This can sometimes go on for years before the carcinoid tumor is found. A tumor usually needs to grow fairly large before it completely blocks (obstructs) the intestine. When that happens, patients have severe belly pain, nausea and vomiting.

Sometimes a carcinoid tumor can block the opening of the Ampulla of Vater, which is where the common bile duct (from the liver) and the pancreatic duct (from the pancreas) empty into the intestine. When this is blocked, bile can back up, leading to yellowing of the skin and eyes (jaundice). Pancreatic juices can also back up, leading to an inflamed pancreas (pancreatitis), which can cause belly pain, nausea, and vomiting.

Sometimes, a carcinoid can cause intestinal bleeding. This can lead to anemia (too few red blood cells) with fatigue and shortness of breath.

The rectum

Rectal carcinoid tumors are often found during routine exams, even though they can cause pain and bleeding from the rectum and constipation.

The stomach
Carcinoid tumors that develop in the stomach usually grow slowly and often do not cause symptoms. They are sometimes found during an exam of the stomach by an endoscopy looking for other things. (Endoscopy is described later in this section.) Some can cause symptoms such as the carcinoid syndrome.

**Signs and symptoms from hormones made by carcinoid tumors**

Some carcinoid tumors can release hormones into the bloodstream. This can create different problems depending on which hormones are released.

**Carcinoid syndrome**

About 1 out of 10 carcinoid tumors release enough hormone-like substances into the bloodstream to cause the symptoms of carcinoid syndrome. These include:

- Facial flushing (redness and warm feeling)
- Severe diarrhea
- Wheezing
- Fast heartbeat

Many people find that factors such as stress, heavy exercise, and drinking alcohol trigger these symptoms. Over a long time, these hormone-like substances can damage heart valves, causing shortness of breath, weakness, and a heart murmur (an abnormal heart sound).

Not all GI carcinoids cause the carcinoid syndrome. For example, rectal carcinoids usually do not make the hormone-like substances that cause these symptoms.

Most cases of carcinoid syndrome occur only after the cancer has already spread to other parts of the body. Normally, blood coming from the GI tract first flows through the liver, where substances made by GI carcinoid tumors are broken down before they can reach the rest of the body. This prevents carcinoid symptoms. But if the cancer spreads outside the intestine (such as to the liver or lungs), the substances it makes can enter the main bloodstream and reach other parts of the body, where it can cause symptoms.

**Cushing syndrome**

Some neuroendocrine tumors produce ACTH (adrenocorticotropic hormone), a substance that causes the adrenal glands to make too much cortisol. This can cause
Cushing syndrome, with symptoms of:

- Weight gain
- Muscle weakness
- High blood sugar (even diabetes)
- High blood pressure
- Increased body and facial hair
- Hump of fat on back of neck
- Skin changes like stretch marks (called striae)

Zollinger-Ellison syndrome

Carcinoid tumors can make a hormone called gastrin that signals the stomach to make acid. Too much gastrin can cause Zollinger-Ellison syndrome, in which the stomach makes too much acid. High acid levels can lead to irritation of the lining of the stomach and even stomach ulcers, which can cause pain, nausea, and loss of appetite.

Severe ulcers can start bleeding. If the bleeding is mild, it can lead to anemia (too few red blood cells), causing symptoms like feeling tired and being short of breath. If the bleeding is more severe, it can make stools black and tarry. Severe bleeding can itself be life threatening.

If the stomach acid reaches the small intestine, it can damage the intestinal lining and break down digestive enzymes before they have a chance to digest food. This can cause diarrhea and weight loss.

- References

See all references for Gastrointestinal Carcinoid Tumor

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How Are Gastrointestinal Carcinoid Tumors Diagnosed?
If you have symptoms that might be from a gastrointestinal (GI) carcinoid tumor, you should see a doctor. He or she will take your medical history and examine you. If the doctor suspects some type of tumor or cancer, some tests will be ordered.

**Medical history and physical exam**

In taking your medical history, the doctor asks you questions about your general health, lifestyle habits, symptoms, and risk factors. The doctor also will probably ask about symptoms of the carcinoid syndrome, as well as symptoms that might be caused by a mass (tumor) in the stomach, intestines, or rectum.

Some patients with neuroendocrine tumors also have cancers or benign tumors of other organs, so doctors may ask about symptoms that might suggest other tumors are present. A thorough physical exam will provide information about signs of neuroendocrine tumors and other health problems. The doctor may pay special attention to the abdomen, looking for a tumor mass or enlarged liver.

If your medical history and physical exam give the doctor reason to suspect you might have a GI carcinoid, some tests will be ordered to find out if the disease is present.

**Imaging tests**

Your doctor may order one or more types of imaging tests to help determine the cause of your symptoms.

**Barium x-ray**

These tests use a barium-containing solution that coats the lining of the esophagus, stomach, and intestines. The coating of barium helps show abnormalities of the lining of these organs. This type of study is often useful in diagnosing some GI carcinoid tumors. It is least effective in finding small intestine carcinoids.

Barium studies can be used to examine the upper or lower parts of the digestive system. You will probably not be able to eat or drink anything (other than water) the night before the test. If the colon is being examined, you may need to take laxatives and/or enemas to cleanse the bowel the night before or the morning of these exams.

**Barium swallow:** This test is used to examine the lining of the esophagus. The patient drinks a barium solution that coats the lining of the esophagus. Then x-ray pictures are
Upper GI series: This test is used to examine the lining of the stomach and the first part of the small intestine. The patient swallows the barium solution, and then may be moved around a bit so that it coats the inside of the stomach. Over time, it will leave the stomach and coat the first part of the small intestine. More x-rays can be taken over the next few hours as the barium travels through the rest of the small intestine. This is called a small bowel follow-through.

Enteroclysis: This is another way to look at the small intestine. In this test, a thin tube is passed from the mouth or nose down through the stomach to the start of the small intestine. Barium contrast is sent through the tube, along with a substance that creates more air in the intestines, causing them to expand. X-rays of the intestines are then taken. This test may be quicker and give clearer images of the small intestine than a small bowel follow-through, but the use of a tube to give the barium makes it more uncomfortable.

Barium enema: This test (also known as a lower GI series) is used to look at the inner surface of the colon and rectum. The barium solution is given as an enema (through the anus) while the patient is lying on the x-ray table. When the colon is about half full of barium, the patient rolls over so the barium spreads throughout the colon. Then x-rays are taken. After the barium is put in, air may be blown in to help spread the barium toward the bowel wall and better coat the inner surface. This is called an air contrast (or double contrast) barium enema. X-rays are then taken.

Barium x-rays are used less these days than in the past. In many cases they are being replaced by endoscopy, where the doctor actually looks into the esophagus, stomach, or colon with a narrow fiber optic scope.

Computed tomography (CT) scan

A CT scan can help tell if the cancer has spread into your lymph nodes or other organs such as your liver.

The CT scan uses x-rays to make detailed cross-sectional images of your body. Instead of taking one picture, like a regular x-ray, a CT scanner takes many pictures as it rotates around you. A computer then combines these into images that look like slices of the part of your body that is being studied.

Before any pictures are taken, you might be asked to drink 1 to 2 pints of a liquid called oral contrast. This helps outline the intestine so that certain areas are not mistaken for
tumors. You might also receive an IV (intravenous) line through which a different kind of contrast dye (IV contrast) is injected. This helps better outline structures in your body. The injection can cause some flushing (redness and warm feeling that may last hours to days). A few people are allergic to the dye and get hives. Rarely, more serious reactions like trouble breathing and low blood pressure can occur. Medicine can be given to prevent and treat allergic reactions. Be sure to tell the doctor if you have any allergies (especially to iodine or shellfish) or if you have ever had a reaction to any contrast material used for x-rays.

A CT scanner has been described as a large donut, with a narrow table that slides in and out of the middle opening. You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken.

When GI carcinoid tumors spread, it is often to the liver. To see if there are areas of cancer spread in the liver, a special type of CT known as a 3D-, 4D-, or multiphase CT scan is done. This means having one set of CT images taken before IV contrast is given. Then more sets of scans are taken as the contrast passes through the liver.

CT scans can also be used to guide a biopsy needle precisely into a suspected area of cancer spread. For a CT-guided needle biopsy, you remain on the CT scanning table, while a doctor moves a biopsy needle through the skin and toward the mass. CT scans are repeated until the doctor is sure that the needle is in the mass. A fine-needle biopsy sample (tiny fragment of tissue) or a core-needle biopsy sample (a larger cylinder of tissue) is removed and looked at under a microscope.

**Magnetic resonance imaging (MRI) scan**

MRI scans use radio waves and strong magnets instead of x-rays to create detailed images of parts of the body. Like a CT scan, an MRI produces cross-sectional slices of the body. As with a CT scan, a contrast material might be injected into a vein, but it is not needed as often.

MRI scans take longer than CT scans, often up to an hour. You may have to lie inside a narrow tube which can feel confining and can upset people with a fear of enclosed spaces. Special, open MRI machine can help with this if needed, although the images might not be as sharp in some cases. The MRI machine makes loud buzzing noises, but some places provide headphones to help block the sound.

Sometimes MRI is used to look at blood vessels in the liver. This requires IV contrast and is known as MR angiography (MRA).
Radionuclide scans

Scans using small amounts of radioactivity and special cameras can be helpful in looking for carcinoid tumors. They can help determine the extent of the tumor, as well as help locate it if doctors aren’t sure where it is in the body.

Somatostatin receptor scintigraphy (OctreoScan®): This is the scan most often used to look for carcinoid tumors. For this scan, a radioactive substance called indium-111 is bound to a hormone-like substance called octreotide. When a small amount of this combined substance is injected into the blood, the octreotide causes it to attach to proteins on carcinoid cells. About 4 hours after the injection, a special camera can be used to show where the radioactivity has collected in the body. More scans may be done over the next few days as well.

I-131 MIBG scan: This is another test that can be used to find carcinoid tumors, but it is used less often than the OctreoScan. This test uses a chemical called MIBG that has radioactive iodine (I-131) attached. This substance is injected into a vein, and the body is scanned several hours or days later with a special camera to look for areas that picked up the radioactivity. These would most likely be carcinoid tumors, although other kinds of neuroendocrine tumors will also pick up this chemical.

Positron emission tomography (PET) scan

A PET scan is another imaging test that uses low levels of radioactivity to look for tumors. PET scans usually use a form of radiolabeled glucose (sugar) to find tumors. But to look for neuroendocrine tumors/cancers, a special type of PET scan is done, using a radioactive form of 5-hydroxytryptophan (5-HTP). This chemical is injected into the bloodstream and is taken up and used by carcinoid cells. After about an hour, a special camera is used to find the areas of radioactivity. Some doctors have found this type of PET scan to be more accurate than CT scans for detecting spread of disease. However, this type of PET scan is not available in every hospital (even some hospitals that have a PET scanner).

Endoscopy

Endoscopy tests use a flexible lighted tube (endoscope) with a video camera on the end. The camera is connected to a monitor, which lets the doctor see any abnormal areas in the lining of the digestive organs clearly. If needed, small pieces of the abnormal areas can be removed (biopsied) through the endoscope. The biopsy samples can be looked at under the microscope to find out if cancer is present and what
kind of cancer it is.

**Upper endoscopy**

This test is also known as *esophagogastroduodenoscopy* or *EGD*. An endoscope is passed down through the mouth to look at the esophagus, stomach, and first part of the small bowel.

An upper endoscopy may be done in a hospital outpatient department, clinic, or doctor’s office. It usually takes 15 to 30 minutes, and most patients are given intravenous medicine to make them feel relaxed and sleepy. If you are sedated for the procedure, you will need someone to take you home (not just a cab).

**Colonoscopy**

This test is also called *lower endoscopy*. A special endoscope known as a *colonoscope* is inserted through the anus up into the colon. The doctor will be able to see the lining of the entire rectum and colon. For a clear view though, the colon must be completely cleaned out before the test. There are different ways to do this, but the most common is drinking a large amount of a laxative solution the night and the morning of the exam.

You will be given intravenous medicine to make you feel relaxed and sleepy during the procedure. A colonoscopy can be done in a hospital outpatient department, clinic, or doctor’s office. It usually takes 15 to 30 minutes, although it may take longer if a tumor is seen and/or a biopsy is taken. Because you will be sedated for the procedure, you will need someone you know to take you home afterward.

**Proctoscopy**

Proctoscopy can be used to look for a rectal tumor. This test uses a shorter, rigid, hollow tube (a proctoscope), which is about 10 inches long and about 1 inch across and may have a light on the end of it. The doctor coats the proctoscope with a lubricant and then gently pushes it into the anus and rectum. By shining a light into this tube, the doctor has a clear view of the lining of the rectum and anus. This test usually requires that you take laxatives or have an enema beforehand to make sure the bowels are empty.

**Capsule endoscopy**

Unfortunately, neither upper nor lower endoscopy can reach all areas of the small
intestine, where many carcinoid tumors begin. A technique known as *capsule endoscopy* may help in some cases.

This test doesn’t really use an endoscope. Instead, the patient swallows a capsule (about the size of a large vitamin pill) that contains a light source and a tiny camera. Like any other pill, the capsule goes through the stomach and into the small intestine. As it travels (usually over about 8 hours), it takes thousands of pictures. These images are transmitted electronically to a device worn around the person’s waist, while he or she goes on with normal daily activities. The pictures can then be downloaded onto a computer, where the doctor can watch them as a video. The capsule passes out of the body during a normal bowel movement and is discarded.

**Double balloon enteroscopy**

This is another way to look at the small intestine. The small intestine is too long (20 feet) and has too many curves to be examined well with regular endoscopy. This method gets around these problems by using a special endoscope that is made up of 2 tubes, one inside the other. First the inner tube, which is an endoscope, goes forward about a foot, and then a balloon at its end is inflated to anchor it. Then the outer tube goes forward to near the end of the inner tube and it is then anchored in place with a balloon. This process is repeated over and over, letting the doctor see the intestine a foot at a time.

This procedure is done after the patient is given drugs to make him or her sleepy and may be even done under general anesthesia (where the patient is asleep). The main advantage of this test over capsule endoscopy is that the doctor can take a biopsy if something abnormal is seen. As with other tests that are done under sedation, you will need someone to take you home after this procedure (not just a cab).

**Endoscopic ultrasound (EUS)**

This test uses an endoscope with a small ultrasound probe on the end. This probe releases sound waves and then uses the echoes that bounce back to create images of the digestive tract wall (or nearby lymph nodes). Putting the ultrasound probe on the end of an endoscope lets it get very close to a tumor. Because the probe is close to the area being looked at, it can make very detailed pictures.

EUS can be used to see how deeply a tumor has grown into the wall of the esophagus, stomach, intestine, or rectum. It can also help see if certain lymph nodes are enlarged and help a doctor guide a needle into lymph node, tumor, or other suspicious area to do a biopsy. You will be sedated for this test, so you will need someone to take you home
(not just a cab).

**Biopsy**

Even if an imaging test finds a mass, it can’t tell if the mass is a carcinoid tumor, some other type of tumor, or an area of infection. The only way to know for sure is to remove cells from the abnormal area and look at them under a microscope. This procedure is called a biopsy.

There are several ways to take a sample from a GI tumor. One way is through the endoscope. When a tumor is found, the doctor can use biopsy forceps (pincers or tongs) through the tube to take a small sample of it. Another way to sample a tumor is with a CT-guided needle biopsy, as described in the section on CT scans.

Bleeding after a biopsy of a GI carcinoid is a rare but potentially serious problem. If serious bleeding occurs, doctors can sometimes inject drugs into the tumor to constrict blood vessels and slow or stop bleeding.

In rare cases, neither endoscopic biopsy nor a CT-guided needle biopsy will be able to get enough tissue to identify the type of tumor. This is sometimes the case with tumors in the small intestine. In such cases, surgery may be needed to remove a tissue sample.

You can read more about biopsies and how they are tested in *Testing Biopsy and Cytology Specimens for Cancer*.

**Blood and urine tests**

Blood and urine tests can be very helpful in diagnosing carcinoid syndrome in patients who have symptoms that might be caused by it.

Many carcinoid tumors, especially those in the small intestine, make serotonin (also called 5-HT). It is probably the cause of at least some of the symptoms of carcinoid syndrome. The body breaks it down into 5-hydroxyindoleactic acid (5-HIAA), which is released into the urine. A common test to look for carcinoid syndrome measures the levels of 5-HIAA in a urine sample collected over 24 hours. Measuring the serotonin levels in the blood may also give useful information. These tests can help diagnose many (but not all) carcinoid tumors. Sometimes, the tumors are small and don’t release enough serotonin for a positive test result.
In other cases, the tumors do not make much serotonin, but they do make its precursor, 5-HTP, which can be converted to serotonin in the urine. In patients with these tumors, the blood serotonin level may be normal, but the urine levels of serotonin and 5-HTP are high.

Some foods, including bananas, plantains, kiwi fruit, certain nuts, avocado, tomatoes, and eggplant, contain a lot of serotonin and can raise 5-HIAA levels in the urine. Medicines, including cough syrup and acetaminophen (Tylenol), can also affect the results. Ask your doctor what you should avoid before having urine or blood tests for carcinoids.

Other common tests to look for carcinoids include blood tests for chromogranin A (CgA), neuron-specific enolase (NSE), substance P, and gastrin. Medicines that lower stomach acid called proton-pump inhibitors (such as omeprazole/Prilosec®, lansoprazole/Prevacid®, esomeprazole/Nexium®, and many others) can make CgA and gastrin levels high even when carcinoid tumors aren’t present. If you take any of these medicines, talk to your doctor about what you need to avoid before having these blood tests. Depending on the tumor’s location and your symptoms, your doctor might do other blood tests as well.

Some of these tests can also be used to show how well treatment is working, since the levels of these substances tend to go down as tumors shrink.

- References
See all references for Gastrointestinal Carcinoid Tumor

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How Are Gastrointestinal Carcinoid Tumors Staged?

Staging — or determining the stage of disease — is the process of finding out if the tumor has spread, and if it has, how far. To help stage the tumor, doctors might use several types of imaging, endoscopy, or other tests described in “How are
The stage of the tumor, along with the place it started, can help determine the prognosis (outlook) for someone with a gastrointestinal (GI) carcinoid tumor. These 2 factors also help the doctor decide what treatment to recommend.

Localized, regional, and distant stages

GI carcinoid tumors can start in several different locations, and until recently there had been no standard system for describing their spread. In the past, many doctors simply divided GI carcinoid tumors into 3 general stages: localized, regional spread, and distant spread. This approach was fairly easy to understand and could be useful when choosing among treatment options.

It might not be possible to tell a benign tumor from a cancer when it is localized because the cells can look the same under the microscope. Any tumor that spreads, though, is a cancer (by definition).

Localized

The cancer has not spread beyond the wall of the organ it started in (for example, the stomach, intestine, or rectum).

Regional spread

The cancer has either spread to nearby lymph nodes or it has grown through the wall of the organ where it started to grow into nearby tissues such as fat, ligaments, and muscle (or both).

Distant spread

The cancer has spread to tissues or organs that are not near where the cancer started (such as the liver, bones, or lungs).

The AJCC TNM system

Modern staging of GI carcinoid tumors uses a system created by the American Joint Committee on Cancer (AJCC) that is known as the TNM system. The TNM system has
3 key pieces of information:

- **T** describes the size of the primary tumor, measured in centimeters (cm), and whether the tumor has grown into nearby organs.
- **N** describes the extent of spread to nearby (regional) lymph nodes.
- **M** indicates whether the cancer has metastasized (spread) to other organs of the body.

Numbers or letters that appear after T, N, and M give more details about each of these factors:

- The numbers 0 through 4 indicate increasing severity.
- The letter X means “cannot be assessed” because the information is not available.
- The letters “is” mean “carcinoma in situ”: the tumor is just in the top layer of cells and has not yet reached deeper layers of tissue.

The T categories for GI carcinoid cancers differ depending on where the cancer starts, but the N and M categories are the same.

**T categories for carcinoid tumors of the stomach**

The T category describes how far down through the stomach layers the cancer has grown. The wall of the stomach is made of 5 layers. From innermost to outermost, they are:

- **Mucosa:** This innermost layer is where stomach acid and digestive enzymes are made. The mucosa has 3 parts: epithelial cells, a layer of connective tissue (the lamina propria), and a thin layer of muscle (the muscularis mucosa).
- **Submucosa:** This is a supporting layer under the mucosa.
- **Muscularis:** This is a layer of muscle that moves and mixes the stomach contents.
- **Subserosa and serosa:** These are the two outermost layers. They act as wrapping layers for the stomach.

**TX:** Primary (main) tumor cannot be assessed due to incomplete information.

**T0:** The primary tumor cannot be found.

**Tis:** The tumor is less than 0.5 mm (about half the width of a grain of rice) and the cancer cells are found only in the top layer of cells of the stomach lining. This is also known as carcinoma in situ or severe dysplasia.

**T1:** The tumor has grown from the top layer of cells and into deeper layers, such as the
lamina propria or the submucosa. The tumor is 1 cm (less than half of an inch) or less.

**T2:** Either:

- The tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm.
- **OR**

- The tumor has grown through the lamina propria and submucosa and into the main muscle layer of the stomach (called the *muscularis propria*).

**T3:** The tumor has grown through the muscularis propria and into the subserosa.

**T4:** The tumor has grown into the serosa (the outer layer of tissue covering the stomach, also called the visceral peritoneum) or into nearby organs or structures.

**T categories for carcinoid tumors of the small intestine**

T categories of small intestine cancer describe the extent of spread through the layers that form its wall.

The layers of the intestine (from innermost to outermost) are:

- **Mucosa:** This is the innermost layer of the intestine. It has 3 parts: the top layer of cells (called the epithelium), a thin layer of connective tissue (called the *lamina propria*), and a thin layer of muscle.
• **Submucosa**: This is the fibrous tissue that lies beneath the mucosa.
• **Thick muscle layers (muscularis propria)**: This layer of muscle contracts to force the contents of the intestines along the tract.
• **Subserosa and serosa**: These are the thin outermost layers of connective tissue that cover the small intestine. The serosa is also known as the *visceral peritoneum*.

**TX**: Primary (main) tumor cannot be assessed.

**T0**: The primary tumor cannot be found.

**T1**: The tumor has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa. The tumor is 1 cm (less than half of an inch) or less.

**T2**: Either:

• The tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm.
• OR

• The tumor has grown through the lamina propria and submucosa and into the main muscle layer of the colon (called the *muscularis propria*).

**T3**: The tumor has grown through the muscularis propria and into the subserosa, the pancreas, and/or the retroperitoneum (the area in back of the abdomen).

**T4**: The tumor has grown into the serosa (the outer layer of tissue covering the intestine, also called the visceral peritoneum) or into nearby organs.

**T categories for carcinoid tumors of the colon or rectum**

*T* categories for carcinoid tumors of the colon and rectum cancer describe the extent of spread through the layers that form its wall. These layers are similar to those found in the wall of the small intestine (see above). From innermost to outermost, they are:

• **Mucosa**: This is the innermost layer of the intestine. It has 3 parts: the top layer of cells (called the *epithelium*), a thin layer of connective tissue (called the *lamina propria*), and a thin layer of muscle.
• **Submucosa**: This is the fibrous tissue beneath the mucosa.
• **Thick muscle layers (muscularis propria)**: This layer of muscle contracts to force the contents of the intestines along the tract.
• **Subserosa and serosa**: These are the thin outermost layers of connective tissue
that cover the large intestine. The serosa is also known as the \textit{visceral peritoneum}.

**TX:** Primary (main) tumor cannot be assessed due to incomplete information.

**T0:** The primary tumor cannot be found.

**T1:** The tumor has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa. The tumor is 2cm (about 4/5 of an inch) or less.

- **T1a:** The tumor is less than 1 cm across (1 cm is less than half an inch).
- **T1b:** The tumor is 1 to 2 cm across.

**T2:** Either:

- The tumor has grown into the lamina propria or submucosa (or both) and is greater than 2 cm.
- **OR**

- The tumor has grown through the lamina propria and submucosa and into the main muscle layer of the colon (called the \textit{muscularis propria}).

**T3:** The tumor has grown through the muscularis propria and into the subserosa or other tissue around the colon or rectum.

**T4:** The tumor has grown through the wall of the colon (or rectum) and into the serosa (also called peritoneum) and/or into nearby organs.

**T categories for carcinoid tumors of the appendix**

**TX:** Primary (main) tumor cannot be assessed.

**T0:** No signs of a primary tumor.

**T1:** The tumor is no more than 2 cm (about 4/5 of an inch) across.

- **T1a:** The tumor is no more than 1 cm across (a little less than half an inch).
- **T1b:** The tumor is larger than 1 cm but not larger than 2 cm across.

**T2:** Either:

- The tumor is larger than 2 cm across but not larger than 4 cm.
- **OR**
The tumor has grown into the cecum (the first part of the large intestine).

**T3:** Either:

- The tumor is larger than 4 cm across.
- OR
- The tumor has grown into the ileum (the last part of the small intestine).

**T4:** The tumor has grown into nearby organs or tissues (such as the abdominal wall).

### N categories for GI carcinoid tumors

**NX:** Nearby (regional) lymph nodes cannot be assessed.

**N0:** The cancer has not spread to nearby lymph nodes.

**N1:** The cancer has spread to nearby lymph nodes.

### M categories for GI carcinoid tumors

**M0:** The cancer has not spread (metastasized) to distant organs or structures.

**M1:** The cancer has spread (metastasized) to distant organs or structures (such as the liver, lungs, bones, etc.).

### Stage grouping

Once the T, N, and M categories for a tumor are known, the information is combined to determine the overall stage. This process is known as *stage grouping*.

### Stage groupings for carcinoid of the stomach

**Stage 0: Tis, N0, M0:** Carcinoma in situ: the tumor is less than 0.5 mm (and the cancer cells are found only in the top layer of cells of the stomach lining (Tis). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage I: T1, N0, M0:** The tumor is 1 cm or less in size and has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).
Stage IIA: T2, N0, M0: Either the tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm in size; OR the tumor has grown into the main muscle layer of the stomach (called the muscularis propria) (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIB: T3, N0, M0: The tumor has grown through the muscularis propria and into the subserosa (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIIA: T4, N0, M0: The tumor has grown into the outer layer of tissue covering the stomach (the serosa or visceral peritoneum) or into nearby organs or structures. The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIIB: any T, N1, M0: The tumor can be any size and may or may not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant sites (M0).

Stage IV: any T, any N, M1: The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

Stage groupings for carcinoid of the small intestine

Stage I: T1, N0, M0: The tumor is 1 cm or less and has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIA: T2, N0, M0: Either the tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm in size; OR the tumor has grown into the main muscle layer of the intestine (called the muscularis propria) (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIB: T3, N0, M0: The tumor has grown through the muscularis propria and into the subserosa (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIIA: T4, N0, M0: The tumor has grown into the outer layer of tissue covering the intestine (the serosa or visceral peritoneum) or into nearby organs or structures. The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIIB: any T, N1, M0: The tumor can be any size and may or may not have grown
into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant sites (M0).

**Stage IV: any T, any N, M1:** The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

**Stage groupings for carcinoid of the colon and rectum**

**Stage I: T1, N0, M0:** The tumor is 2 cm (about 4/5 of an inch) or less and has grown into the lamina propria and may have grown into the submucosa (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIA: T2, N0, M0:** Either the tumor has grown into the lamina propria or submucosa (or both) and is greater than 2 cm; OR the tumor has grown into the main muscle layer of the colon (called the *muscularis propria*) (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIB: T3, N0, M0:** The tumor has grown through the muscularis propria and into the subserosa or other tissue around the colon or rectum (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIIA: T4, N0, M0:** The tumor has grown through the wall of the colon (or rectum) and into the serosa (also called *peritoneum*) and/or into nearby organs (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIIB: any T, N1, M0:** The tumor can be any size and may or may not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant sites (M0).

**Stage IV: any T, any N, M1:** The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

**Stage groupings for carcinoid tumors of the appendix**

**Stage I: T1, N0, M0:** The tumor is no more than 2 cm across (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage II: T2 or T3, N0, M0:** The tumor is either larger than 2 cm across or has grown into the cecum (T2), or it is larger than 4 cm across or has grown into the ileum (T3).
The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage III:** Either:

**T4, N0, M0:** The tumor has grown into nearby organs or tissues, such as the abdominal wall (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**OR**

**Any T, N1, M0:** The tumor can be any size and may or may not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant sites (M0).

**Stage IV: Any T, any N, M1:** The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

- **References**
  See all references for Gastrointestinal Carcinoid Tumor

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**Survival Rates for Gastrointestinal Carcinoid Tumors**

Survival rates are often used by doctors as a standard way of discussing a person’s prognosis (outlook). Some people with cancer may want to know the survival statistics for people in similar situations, while others may not find the numbers helpful, or may even not want to know them. Stop reading here and go to another section if you decide that you do not want to know them.

The 5-year survival rate refers to the percentage of patients who live at least 5 years after their cancer is diagnosed. Of course, many people live much longer than 5 years
(and many are cured). Also, people who have this cancer can die from something else. These survival rates, called observed survival rates, do not take this into account.

To get 5-year survival rates, doctors have to look at people who were treated at least 5 years ago. Improvements in treatment since then may result in a better outlook for people now being diagnosed with carcinoid tumors.

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they can’t predict what will happen in any particular person’s case. Many other factors can affect a person’s outlook, such as treatment received, the grade of the tumor and its growth rate, and the patient’s age and health. Your doctor can tell you how the numbers below may apply to you, as he or she is familiar with your situation.

Most GI carcinoid tumors are found while they are still localized, but this varies based on the organ they start in. Tumors of the stomach, duodenum (the first part of the small intestine), appendix, and rectum are likely to be found before they have spread. In contrast, many tumors of other parts of the small intestine (the jejunum/ileum) and the colon (including the cecum) have already spread to nearby tissues or lymph nodes or to distant sites when they are first diagnosed.

The following 5-year survival rates are based on people diagnosed with carcinoid (well and moderately-differentiated neuroendocrine tumors) between 1988 and 2004:

### 5-year observed survival rates for carcinoid tumors

<table>
<thead>
<tr>
<th>Site</th>
<th>Localized</th>
<th>Regional</th>
<th>Distant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach</td>
<td>73%</td>
<td>65%</td>
<td>25%</td>
</tr>
<tr>
<td>Duodenum</td>
<td>68%</td>
<td>55%</td>
<td>46%</td>
</tr>
<tr>
<td>Jejunum/ileum</td>
<td>65%</td>
<td>71%*</td>
<td>54%</td>
</tr>
<tr>
<td>Cecum</td>
<td>68%</td>
<td>71%*</td>
<td>54%</td>
</tr>
<tr>
<td>Appendix</td>
<td>88%</td>
<td>78%</td>
<td>25%</td>
</tr>
<tr>
<td>Colon</td>
<td>85%</td>
<td>46%</td>
<td>14%</td>
</tr>
<tr>
<td>Rectum</td>
<td>90%</td>
<td>62%</td>
<td>24%</td>
</tr>
</tbody>
</table>

*The 5-year survival for these tumors at the regional stage is slightly better than for the localized stage, although the reason for this is not exactly clear.

• References

See all references for Gastrointestinal Carcinoid Tumor
What Should You Ask Your Doctor About Gastrointestinal Carcinoid Tumors?

It is important to have honest, open discussions with your cancer care team. They want to answer all of your questions, no matter how trivial you might think they are. For instance, consider these questions:

- What kind of carcinoid tumor do I have?
- What is the stage of my carcinoid tumor and what does that mean to me?
- What are my treatment choices?
- What do you recommend and why?
- Based on what you’ve learned about my tumor, what is my prognosis (outlook)?
- What risks or side effects are there to the treatments you suggest?
- How will treatment affect my daily activities?
- What are the chances my tumor will recur with these treatments?
- What should I do to be ready for treatment?

In addition to these sample questions, you might write down some of your own. For instance, you might want more information about recovery times so you can plan your work schedule. Or you might want to ask about second opinions or if you qualify for any clinical trials.

References
See all references for Gastrointestinal Carcinoid Tumor

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